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Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: connecting the dots

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Neonatal intensive care unit (NICU) discharge readiness is defined as the masterful attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the primary caregivers at the time of discharge. NICU discharge preparation is the process of facilitating comfort and confidence as well as the acquisition of knowledge and skills to successfully make the transition from the NICU to home. In this paper, we first review the literature about discharge readiness as it relates to the NICU population. Understanding that discharge readiness is achieved, in part, through successful discharge preparation, we then outline an approach to NICU discharge preparation.

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INTRODUCTION

In 2010, almost 12% of the nearly 4 million births in the United States were preterm, defined as delivery at <37 weeks completed gestation.[1] Compared with their full-term counterparts, preterm infants present special challenges to their families and care providers.[2] Many preterm infants require care in the neonatal intensive care unit (NICU) after delivery. For the families of these >400 000 infants each year, specialized support and education is required to provide proper care in the home environment.

Although there is no uniform definition of discharge readiness, it usually relates to both the baby's clinical condition and the caregiver's confidence and competence in caring for the infant after discharge. In this paper, we focus solely on the caregiver's discharge readiness. NICU discharge readiness is defined as the masterful attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by the primary caregivers at the time of discharge. NICU discharge preparation is the process of facilitating discharge readiness to successfully make the transition from the NICU to home. Discharge readiness is the desired outcome, and discharge preparation is the process. In this paper, we first review the literature about discharge readiness as it relates to the NICU population. Understanding that discharge readiness is achieved, in part, through successful discharge preparation, we then outline an approach to NICU discharge preparation.

NICU DISCHARGE READINESS

Discharge readiness and outcomes

Several studies have demonstrated that adverse outcomes are associated with unreadiness at hospital discharge. In the adult population, lack of discharge readiness, combined with patient characteristics, explain 16% of post-discharge coping difficulties.[3] Adult patients who are unprepared for discharge are less likely to understand their discharge medications or their primary care follow-up plan and recall their chief discharge diagnoses.[4] For these adults, medication errors also occur more frequently.[4]

Discharge unreadiness has also been shown to be associated with increased health-care utilization. For example, readmission in the first 30 days after hospital discharge—considered to be unplanned, potentially avoidable and costly—has been shown to be partially attributable to inadequate discharge preparation, including lack of patient and family readiness and poor discharge coordination.[5] In fact, well-designed discharge preparation programs have been shown to reduce rates of hospital readmissions and emergency department visits while increasing the rate of primary care follow-up,[4] thereby reducing health-care costs.[5]

Although not as well studied as the adult population, discharge readiness in the newborn population is also a significant contributor to the successful transition home from the hospital. Newborns' parents who are perceived either by themselves or their providers as less prepared for discharge experience more difficulty post-discharge.[6–8] For instance, in one study mothers of term infants who felt less ready for discharge reported greater difficulties with stress, recovery, self-care, confidence with self-care management abilities, coping with challenging family-related issues, obtaining necessary help and emotional support, and overall adjustment in the first 3 weeks after discharge.[9] Mothers who were not ready for discharge experienced greater difficulty in coping with the care of their infant and felt less confident about their infant care abilities.[7,9] These mothers of term infants identified themselves as being less happy,[7] made twice as many phone calls to their pediatric care providers on behalf of their infants,[7] placed their infants in the prone sleeping position more often,[7] and had a higher likelihood of a newborn emergency room or urgent care visit[9] during the month after discharge. Another study showed that even after accounting for potential confounders such as maternal sociodemographic, prenatal, perinatal and postpartum factors, discharge unreadiness was

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associated with increased infant-related calls to health-care providers and infant symptom days.[8] Among families with preterm infants, lack of readiness for NICU discharge was associated with more infant feeding-related issues in the days after NICU discharge.[10]

There are also economic implications associated with discharge readiness. It is been well documented that preterm infants are already at high risk of re-hospitalization after initial discharge.[11–13] Advances in technology available for home care and pressure from payers for shorter lengths of hospital stay have led to expedited discharges. Furthermore, the push for earlier home discharge of even complex NICU babies goes back over 30 years. In one of the earliest cost-effectiveness publications regarding home management of bronchopulmonary dysplasia, a significant reduction in length of stay was demonstrated, even after adjusting for the readmission of some of the patients.[14] Although length of stay has not been independently associated with discharge readiness,[8,15] parents of medically complicated infants may require more time to achieve appropriate discharge readiness because of the complex discharge preparation needed to handle the medical exigencies of their infants. Currently, the staff makes the necessary effort to ensure that families with medically complicated infants are ready for discharge.[15] Without this effort, inadequate readiness at discharge could result in cost shifting from the insurer and hospital to the family in terms of the additional equipment and supplies needed at home as well as time missed from work.[16]

If the family–caretakers are properly prepared for discharge, regardless of the complexity of the child, health-care costs may be mitigated by reducing the following: (1) the costs associated with increased length of stay by having the preparation take place earlier in the hospitalization; (2) the costs associated with more expensive post-discharge health-care utilization, including unplanned provider visits, emergency room visits and re-admissions; (3) the family costs associated with missed work and out of pocket expenses.

Risk factors for discharge unreadiness

Any family with an identifiable risk factor for discharge unreadiness should receive special attention during the discharge planning process to ensure they achieve the best possible outcomes. As discharge unreadiness is influenced by aspects of the infant's care requirements, discharge preparation and family characteristics, these factors can be used identify families at increased risk for being unready for discharge.

High-risk families. Families at higher risk for discharge unreadiness include those affected by the following conditions: substance abuse, inadequate prenatal care, teenage pregnancy, domestic violence, marital instability, mental health issues especially anxiety or depression, and lower socioeconomic status or illiteracy.[8,17–20] A family with anxiety, depression and/or post-traumatic stress from the overwhelming experience of the NICU may have limited ability to connect with and parent their infant.[21] Maternal anxiety related to her NICU experience persistently affects a mother's parenting ability and interaction with her child even at 24 months corrected age.[18]

As the demographics of the United States change, families with limited English proficiency will likely increase. A recent study demonstrated that Spanish-speaking mothers were less likely to feel prepared for discharge.[19] Spanish-speaking mothers reported that 67% of the time, they were communicated with in English despite needing an interpreter 'all the time' (75% of Spanish-speaking mothers) or 'most of the time' (19% of Spanish-speaking mothers).[19] Although Spanish-speaking families were more likely to report that staff were friendly and available, they felt uncomfortable asking questions of the nurses and were less able to participate in decisions regarding their infant's care when compared with English-speaking families.[19] Finally, language barriers interfered with appropriate medical follow-up arranged by the NICU.[19] For example, in one instance, a mother with limited English proficiency misunderstood her discharge teaching and thought her infant was to stay in a Holter monitor without bathing for 6 weeks instead of the intended 72 h.[19]

Moderate-risk families. Moderate-risk families include those with the following characteristics: black non-Hispanic maternal race/ethnicity, maternal history of chronic disease, primigravid status, inadequate prenatal care, delivery during non-routine hours, in-hospital neonatal problems and intent to breastfeed.[22] Families are also at elevated risk for discharge unreadiness when either their discharging nurse is not a skilled teacher or when the content of the discharge teaching is inadequate to meet the families' needs.[6,9]

Routine-risk families. Families that are not included in the high- or moderate-risk categories are considered routine risk. Factors associated with routine risk for discharge unreadiness include the following: confidence in the infant's health and maturity, their selected pediatrician, and the home environment,[15] and higher socioeconomic status.[6]

Assessment of discharge readiness

It is important to assess and account for a family's risk for inadequate discharge readiness when planning discharge. Formalizing the assessment of discharge readiness could facilitate identification of families at risk for readmission or emergency room utilization before discharge when anticipatory interventions could prevent avoidable post-discharge health-care utilization.[5]

There are challenges associated with discharge readiness assessment. Although several instruments to assess discharge readiness are available, the majority of them are intended for adult patients.[3,5,23] Of those that are designed for newborns, most are intended for term infants.[9,22] In addition, the limited number of measures designed for a NICU population, have not been standardized, validated and supported by preterm infant outcomes.[6,15,17,24]

Regardless of these limitations, it is still important for a NICU to choose a method of assessment and to systematically assess the discharge readiness of all families whose infants are soon to be discharged home. This approach will, at minimum, provide the NICU with a relative assessment of a family's discharge readiness compared with other families being discharged from the NICU. This local data can be used in conjunction with risk factors to anticipate which families may experience more difficulties following discharge and may benefit from greater in-hospital and post-discharge support for a successful transition home.[5] In addition, a NICU can also use the results of the assessment tool to improve aspects of its discharge preparation process that were deemed by families as inadequate or unhelpful.

The assessment of discharge readiness is best when including a self-evaluation by the family as well as a staff assessment of the family given that families and staff often have different perceptions of the family's discharge readiness.[15,17,24] In the adult population, staff discharge assessment is more strongly associated with post-discharge health-care utilization than the patient's self-assessment.[5]

NICU DISCHARGE PREPARATION

The positive outcomes associated with discharge readiness make the case for a carefully structured and executed comprehensive discharge preparation program. The American Academy of Pediatrics (AAP) first published guidelines for the hospital

discharge of the high-risk infant in 1998[25] (updated in 2008[26]). The goal of discharge preparation is to enable families to feel ready to assume total care of their infant at discharge and to make a successful transition from NICU to home.[6]

The decision to discharge is made by the medical team but may be influenced by utilization management payer criteria for continued hospitalization. In their guidelines, the AAP recommends discharge of infants when they are able to ingest sufficient oral feeding to support appropriate growth, coordinate oral feeding and breathing, maintain normal body temperature in a home environment and have stable cardiorespiratory function.[26] Furthermore, infants need an active program of family involvement and preparation for care at home, arrangements for a physician or other health-care professional who is experienced in the care of high-risk infants to assume health-care after discharge, and an organized program of surveillance to monitor growth and development.[26]

In this section, we summarize the AAP recommendations regarding NICU discharge and supplement them with literature that augments the guidelines with specific practical examples of implementation. The overall focus is on the discharge preparation of the family and not on the NICU care of the infant. Since late preterm infants, defined as infants born between 34 0/7 and 36 6/7 weeks, are cared for in newborn nurseries rather than in the NICU in many hospitals, the AAP recommends specific criteria for discharge of these infants.[27] As we focus on NICU discharge, the discharge process of the newborn nursery is not covered in article.

A NICU discharge preparation program should be manageable and useable on a large scale because if it is labor intensive, confined to a limited group of administrators and difficult to scale, it is unlikely to be successful.[28] Discharge preparation can be divided into two broad areas: (1) discharge teaching for the family to care for the infant, and (2) coordination/transfer of care to post-discharge medical providers.

Part I: discharge teaching

Discharge teaching structure. The discharge teaching structure includes consideration the following: family-centered care, the discharge planning team and discharge teaching strategies including checklist use (Supplementary Appendix 1), skills demonstration and the support of families with limited English proficiency. One of the first objectives of discharge teaching is to identify those who will be caring for the infant after discharge. It is preferable that at least two individuals are identified and are familiar with the infant's care in the event one is unavailable.[26]

Family-centered care: Family-centered care is a philosophy that recognizes that parents and staff are partners in providing care for infants.[29] The family is the most important and consistent factor in each infant's life.[30] Therefore, involving the family in the care of their infant in the NICU is paramount. The four central tenets of family-centered care are dignity and respect, information sharing, family participation in care, and family collaboration.[29] When implemented properly, family-centered care can shorten the length of stay, decrease the risk for readmission, enhance breastfeeding outcomes, boost families' confidence with infant care and increase staff satisfaction.[31] For example, family presence and participation in medical rounds is an opportunity to help prepare families for the transition home.[21,29,30] Engaging families in the discharge planning process may decrease their anxiety related to discharge.[32]

Discharge planning team: In addition to the family, the discharge planning team may include clinical nurses, physicians, mid-level providers (for example, neonatal advance practice nurses and physician assistants), case managers and other providers as appropriate.[26] Primary and nursing team members who are familiar with the family and infant's history, experiences, strengths, and weaknesses allow for consistent ongoing technical assistance and emotional support to families.[33,34] It is preferable for the discharging nurse to be the primary nurse or a staff nurse who is familiar with the family.[15,34,35] When feasible, including the discharge coordinator and the primary care provider in the discharge planning helps make for a smoother transition home.[35] The AAP defines the medical home as an approach to providing comprehensive primary care where the pediatric care team works in partnership with a child and a child's family to assure that all of the medical and non-medical needs are met.[36] For the sake of this article, the terms primary care providers and medical home will be used synonymously. Nurse educators are registered nurses with advanced training who manage the education of the staff nurses, provide clinical supervision and serve as an additional resource for the NICU discharge team.

Although the entire medical team is responsible for the discharge preparation of the family, nurses are generally the primary educators of families. Barriers to discharge preparation include limited time available to staff for teaching and variability of staff knowledge levels and teaching skills. To mitigate this variability, standardized teaching material ought to be available.[37] These materials ensure consistent content coverage and may be modified as necessary for a specific family's circumstance.[10] To provide a standardized discharge framework, a discharge planning task worksheet can help ensure that all the pertinent topics are covered and can be utilized by any staff member (Supplementary Appendix 2).

As the same staff member who provides patient care is also responsible for family teaching, acute medical demands may compete with family education.[24] Consequently, a high census, increased patient-to-nurse ratio, clinical documentation and administrative requirements are all likely to compete with teaching time.[24] Staff assignments have to allow for appropriate patient-to-nurse ratio and patient acuity balance to allow time for teaching.

Discharge teaching strategies and the individualized teaching plan: Discharge teaching should begin shortly after admission and continue until families are prepared to bring their infants home. Each family deserves a structured education program[32,38] that is tailored to their specific circumstance[26,32] with frequent evaluations of progress and the capacity for adjustment as necessary.[39] This education plan includes all the skills and knowledge the family is expected to master before discharge (see discharge teaching content). The individualized discharge plan ought to be readily available to the family reasonably early during the NICU hospitalization to give them an idea of what they will be expected to learn before discharge.[10,24,39] Gradual introduction of information and skills early in the hospital course will allow families enough time to gain the necessary knowledge, skills and confidence while preventing them from being overwhelmed with teaching in the days just before discharge.[24]

A. Checklist and outlines: The tasks and knowledge that families are expected to master could be listed on a checklist or outline (Supplementary Appendix 1).[26] As the amount of educational content can be overwhelming for a family when presented *en masse*, a written checklist or outline serves the dual purpose of allowing a gradual introduction of all the necessary content and providing a method to track progress.[10,24,39] Furthermore, a written checklist or outline allows for more complete instruction.[26] As teaching is usually conducted by more than one staff person, coordination of the teaching effort is essential.[40] A checklist provides a tangible efficient method to make all the educators aware of what has been and still needs to be taught.

B. Skill demonstration and written supplementation: After receiving instruction with infant care skills, families ought to be repeatedly

provided with adequate opportunities to practice their skills with direct supervision because repetition and return demonstrations (that is, teach-back technique) increase the retention of the material.[26,32,34,37] Families rooming-in may afford them extra time with their infant to master infant care skills.[26] When possible, rooming-in 3 to 4 days before discharge may also help the family feel more confident and comfortable with the transition home.[34] It also provides an opportunity to address their discomfort or their lack of mastery of certain skills by providing additional practice. Finally, supplementing discharge teaching with either written or recorded information presented in a manner that is simple, clear and devoid of medical jargon is another means of reinforcing the teaching and consequently increasing retention of the material.[24,34,41]

C. Supporting families with limited English proficiency: As discharge materials are generally designed for families with English proficiency, those families with limited English proficiency may not receive adequate discharge preparation without special consideration. Appropriately trained interpreters should be involved in all discharge teaching.[19] It is also recommended that families' comprehension of the teaching and awareness of scheduled medical follow-up appointments be confirmed by return demonstrations of their knowledge with interpreters.[19] Ideally, all written discharge materials should be provided to families in their preferred language.[19]

Discharge teaching content. Parents who receive more discharge teaching content than they perceive they require, are more ready for discharge[6] underscoring the importance of the discharge teaching content. Much of the discharge preparation content is influenced by the AAP guidelines.[26] The discharge teaching content is listed in Table 1.

Technical baby care skills: Families need a working knowledge of both important basic infant care giving skills—including breast and/or bottle feeding; mixing formula; bathing; dressing; caring for the skin, the umbilical cord and the genitalia; and placing the infant in a safe sleeping position—and handling any special care situations such as utilizing medical equipment and administering, as well as storing medications correctly when necessary.[24,26,35,42,43] Research suggests that most families are adept with the necessary technical skills at the time of discharge.[15] However, the infant's post-discharge feeding and nutritional requirements[44] need special emphasis because feeding and nutrition-related issues are the most common problems reported after discharge.[10] Finally, families benefit from training in infant cardiopulmonary resuscitation.[26] It has been reported that 21% of infants born between 24 and 36 weeks gestation have at least one apparent life-threatening event after NICU discharge.[44] Ideally, the cardiopulmonary resuscitation instruction will occur before discharge from the NICU.

Table 1. Discharge preparation content

Technical baby care skills
Basic infant care giving skills
Handling any special care situations
Cardiopulmonary resuscitation
Home environment preparation
Supplies and equipment they will need at home
Where to acquire provisions to address special needs
Emergency contingency plans
Community resources
Carbon monoxide and smoke detectors
Car seat/bed use
Car seat or car bed evaluation
Installation of car seat or car bed
Preterm infant behavior: normal and abnormal
Typical infant behaviors
How normal preterm behavior differs from term infant
Abnormal infant behavior
Anticipatory guidance
What to expect at home
Parental mental health
Coping with and soothing their crying infant

Home environment preparation: Families should receive instruction on which supplies they will need at home including feeding supplies as appropriate (for example, breast pump, nipples/bottles, formula, and so on), crib or bassinet (safety approved), diapers, baby clothes, thermometer and a suction bulb.[26,35] Ideally, these supplies would be acquired before discharge to prevent families from scrambling during the first few days of having their infant home. Families should be instructed on where to acquire provisions to address special needs at home (medications, pumps and other equipment, monitors, and oxygen) as well as what to do when supplies are depleted or equipment malfunctions.[26,35] In the event of a life-threatening emergency associated with equipment malfunction, families ought to have instruction on emergency procedures (for example, cardiopulmonary resuscitation), the availability of community resources, and a list of relevant individuals or organizations to call with questions and concerns.[24,26,35] Finally, the importance of carbon monoxide and smoke detectors should be emphasized so that they are purchased and installed before discharge.[45]

Car seat/car bed use: Families deserve clear and consistent information about car seat and car bed use.[10] Staff must ensure that car seats have not exceeded their expiration dates and that the infant fits properly in the car seat.[43] Before discharge, each preterm infant requires a car seat or car bed evaluation as is appropriate.[26,43,44] This evaluation (also referred to as a 'test' or 'challenge') consists of placing the preterm infant securely into the car seat or car bed at the proper angle for riding; adjusting the straps so they are in the correct position on the baby; and monitoring the infant's vital signs (for example, heart rate, breathing and oxygen saturation). If the infant is able to tolerate being in the car seat or car bed for minimum of 90 to 120 min or for the duration of anticipated travel, whichever is longer without any episodes of apnea, bradycardia or desaturations, then he has passed the evaluation.[43]

The evaluation preferably occurs at least 1 day before discharge to allow the family sufficient time to acquire an alternative car seat or bed if a problem is found with the first one. Finally, some families will benefit from further assistance or instruction about how to properly install the car seat/bed in their car. Car seats often have bases that can be installed before the infant being discharged.

Given that clearly defined national guidelines on the use of a car seat versus a car bed do not exist, individual neonatal units have to rely on their own local guidelines. Furthermore, recommendations on when or how to transition an infant from the car bed to a car seat are lacking. Until more data are available, individual providers may use their own discretion with the help of subspecialists. Primary care providers may request guidance from the NICU clinicians about when and how to transition infants from car beds to car seats.

Preterm infant behavior: normal and abnormal: Families require instruction about typical infant behaviors including common breast and bottle feeding patterns, normal bowel and bladder function, and usual preterm infant sleep–wake cycles.[26] Families ought to be aware that preterm infants frequently do not engage socially in the same way as term infants.[21] They are also often less active, alert and responsive than term infants.[21] Furthermore, preterm infants can be more irritable and have more gaze aversion than term infants.[21] Research has shown that

such behaviors may cause anxiety and fear in families who are not knowledgeable about normal preterm infant behavior.[21] Therefore, families also benefit from instruction on how normal preterm behavior differs from term infant behavior even when the preterm infant's postmenstrual age is corrected to term. In contrast, some behaviors, conditions and physical signs are not normal for any infants including those born preterm, and families may also need to be taught to recognize worrisome departures from normal behavior and to seek medical attention (Table 2).[24,26,35]

Anticipatory guidance: Anticipatory guidance in the context of NICU discharge preparation refers to helping the family develop a realistic idea of what their home life will be like with their preterm infant during the immediate as well as longer-term period following discharge. It is suggested that 1 week before anticipated discharge, families be given an overview of what to expect in the weeks, months and first year of life after discharge.[39] This education may include anticipated and potential developmental issues, any potential growth-related concerns, expected number and type of physician visits including those related to routine infant health maintenance.[39] Special emphasis could be placed on expected changes in feeding habits during the first few weeks home including targeted feeding volumes that promote growth yet avoid overfeeding.[32] Adequate discharge planning can reduce feeding problems as well as maternal disruptive feeding behaviors—such as decreasing non-contingent interruption of feeding and aberrant attempts to stimulate their infants' sucking.[28] A developmental specialist such as an occupational or physical therapist may be helpful to families during their transition by answering questions about future infant development.[33]

Families may also be given anticipatory guidance related to mental health. Maternal mental health is a significant issue for mothers with preterm infants, and research suggests that post-partum depression may be more prevalent among mothers who deliver preterm infants compared with term infants.[46] Maternal mental health problems such as depression and anxiety can result in poor bonding and attachment between mother and infant.[46] Also, there is growing body of literature to support that living with fathers with depressive symptoms and other mental health problems is associated with child behavioral problems.[47] Therefore, it is important that parents who have depressive symptoms be referred to and assessed by appropriate mental health professionals.[46]

There are periods after discharge when the family will be fatigued and easily frustrated by normal infant behavior such as crying and frequent nighttime awakenings. Families must be advised on how to cope with and soothe their crying infant to help prevent harm caused by shaking, slamming, hitting or throwing the infant.[48] In addition, families should be informed of available community resources, which they can call in the event that they are overwhelmed and unable to cope with the care of their infants.

Table 2. Worrisome infant changes in behavior, physical signs and abnormal observations

Changes in behavior
Not hungry or eating less well than normal
Sleepier or less active than usual
More irritable or fussy than usual
Physical signs
Difficulty breathing
Cyanosis (blueness) of the lips or mouth
Flushed, very pale or mottled (spotted or blotched) skin
Less muscle tone than usual
Abnormal observations
Vomiting and/or diarrhea
Dry diapers for >12 h
No stool for >4 days
Black or bright red stool
An axillary (armpit) temperature over 100° Fahrenheit
A rectal temperature under 97° Fahrenheit

Adopted from references 24, 26, 35.

Discharge teaching process. It is important to remember that preparation for discharge should begin soon after admission. The discharge teaching process must be tailored to account for the resources available in each unit and the learning style of the family. Throughout the hospitalization, there will be opportunities for both formal and informal teaching. By having a mix of teaching/learning approaches (for example, lectures, small group classes, self-guided study, audio/video learning, and so on) available, a unit will greatly increase its ability to prepare a family.

Bedside teaching by the staff is one of most impactful teaching methods available in the NICU. This close observation type of instruction allows the staff to get cues from the family about what they know, want to know and need to know as well as clues on how to present the information.[40] By clustering the teaching within the context of care, staff can add relevance to the subject matter and make each interaction with the family a teachable moment.[40] Informing families of this informal teaching/learning part of the discharge process will allow them to become more engaged in the learning process, and encourage more retention of the material.[40] In the following section, we offer some other creative ideas for consideration.

Discharge planning meetings: Families often report that they feel their infant's discharge date abruptly appeared. As nurses incrementally prepare families for discharge, families may not recognize the teaching that is occurring as 'discharge preparation.' Discharge planning meetings are one way to formalize the discharge preparation process by providing families with discharge information, allowing them to focus on discharge preparation, and ultimately feel more prepared for discharge. Discharge planning meetings need to occur early enough during the hospitalization to allow for further discharge instruction as needed. Once the infant and family are approaching readiness for discharge, a member of the medical team could organize the discharge planning meeting. During the meeting, the medical team could review with the family all the previously completed discharge teaching, explain what topics are remaining, address any concerns or questions that the family may have, and give the family an idea of the discharge timeline. Often, staff nurses are the best positioned to hold a discharge planning meeting.

Discharge binders/folders: A binder or folder is one method to provide families with all of their written discharge material consolidated into a central repository. This information could be provided on admission, during the discharge planning meeting or at a time when specific criteria is met. The content may be determined by the individual units. Some of the recommended content includes the following: a handout that explains discharge criteria, a checklist or other method of keeping track of discharge teaching topics that need to be covered before discharge, a place to store written materials that supplement teaching, a list of commonly asked questions, and a community resource list.[10,26,39] If this information is provided at or near the time of NICU admission, then it is also reasonable to include an introduction to the culture of the NICU with an explanation of who the different staff members are and what to expect on a daily basis, a glossary of definitions pertaining to the NICU, a handout that explains discharge criteria along with an expected NICU length of stay, a method (that is, chart or journal) for tracking and communicating the infant's progress, and a hospital resource list.[10,26,39]

Social work involvement: The involvement of a social worker early in the NICU stay can help the transition process for families. The social worker may help the family better adjust to the stressful nature of the NICU by speaking with them about the range of feelings they may experience as well informing families of available resources in the event that the usual coping strategies are insufficient.[49,50] Social work also facilitates the coordination of community resources and services for the family. In many units, the social worker also serves as the case manager by assessing the family's post-discharge needs and implementing a discharge care plan.

Home assessments: A home assessment by a discharge coordinator or case manager can be a helpful component of the discharge planning process because it helps determine the level of support called for in the home and can identify issues that a visiting nurse or early intervention specialist could monitor.[35]

Mentoring programs: Voluntary participation in a family-to-family mentoring program may provide some families with emotional support by learning about other families' experiences.[33,51] Many former NICU families are eager to volunteer to help other families. Families going through the NICU experience often appreciate discussions with an informed non-medical contact and may also continue to benefit from the mentoring process after hospital discharge.

Part II: transfer and/or coordination of care

When infants, especially those with unresolved or ongoing medical issues, are discharged home, a home care plan as well as appropriate medical follow-up should be arranged in collaboration with the family.[26] It is imperative that the NICU medical team coordinate care with the medical home to help ensure optimal continuity of care. One of the most common complaints about the transitioning process from the NICU to home is the lack of communication between the NICU staff and the primary care provider.[50] As recommended by the AAP, the plan for unresolved and ongoing medical issues should be developed with or at least communicated to the primary care provider.[26]

Primary care providers and the medical home. The AAP recommends that high-risk infants receive their primary care in a medical home with a primary care provider who has expertise in caring for patients who have had NICU care.[26] Families who do not have an established relationship with a primary care provider may benefit from help in deciding on a specific provider. Those families may be advised, when possible, to discuss their specific situation with the potential primary care provider before joining the practice as some providers may not feel comfortable with NICU graduates because of a lack of experience/training, insufficient infrastructure to support more than basic care or geographic limitations.[50] After a primary care provider is identified, the discharge process can be greatly helped by having that provider become involved with the family before discharge.[34]

The communication between the NICU team and the primary care provider should at minimum include a written discharge summary[10,49] and a phone call or in-person meeting for complex medical or social situations. The content of the discussion with the infant's primary care provider could include the infant's medical history, ongoing medical issues, discharge medications and follow-up appointments (both those scheduled and those yet to be arranged).[44] The primary care provider may also be informed of all nutritional recommendations and guidance given to the family, and any discharge teaching that may benefit from reinforcement after discharge.[35,44]

Subspecialty care. In addition to primary care physicians, some infants may require additional care from pediatric subspecialists. As infants with retinopathy of prematurity are at increased risk for blindness, close follow-up is necessary. At the time of discharge, it is important to make follow-up ophthalmology appointments and to document them in the medical record and discharge summary. Failure to arrange or comply with appropriate ophthalmology follow-up not only puts the infant at risk for a poor visual outcome, but also places the discharging provider at medical-legal risk.[44] Infants with ongoing respiratory issues such as chronic lung disease would benefit from the care of a pulmonologist.[52] Infants with intraventricular hemorrhage, post-hemorrhagic hydrocephalus, white matter injury and/or any other neurologic issues may benefit from follow-up with a neonatal or pediatric neurologist.[53]

Discharge summary. The discharge summary is a valuable means of communicating relevant information to both the family and providers who care for the infant after discharge. The summary is also helpful to other medical providers if the infant is visiting the emergency room, planning a surgery or consulting with a medical specialist.

Having a standardized format for the discharge summary improves clarity and helps to ensure that all the pertinent information is included and organized in a useful manner[10,33] (Supplementary Appendix 3). In the discharge summary, include a synopsis of the medical course, including the maternal history, infant's birth history, infant's neonatal history, discharge diagnoses and the infant's condition at discharge as well as prognosis if it is guarded or grim.[33,49] Also include the infant's discharge medications and dosages, medical equipment needs (for example, oxygen, gastrostomy tube, and so on), and home feeding plan. It is preferable to also include follow-up appointments that were either arranged before discharge or recommended but not yet arranged.

The newborn hearing screen results, dates and (if known) results of state newborn screenings, any immunizations administered during the hospital stay and any pending test results, as well as referrals to community service programs (for example, community health nursing agencies, early intervention services) should be documented.[10,33] Also note if the infant has any special or atypical needs (for example, a medically indicated sleep position) or behavioral observations.[33] Consider documenting relevant observations of family function by the medical staff including their psycho–social support network, challenging elements of the home environment (for example, domestic violence, substance use), social service involvement and difficult financial situations (for example, unemployment).[33,49] Finally, any physical or occupational therapy services may also be included.[33]

Before distributing the document, the discharge summary ought to be checked for errors and omissions to ensure that the document is as accurate as possible. The family may be provided with a copy of the discharge summary at their discharge from the NICU. To facilitate communication of important information, it is helpful to provide a copy of the discharge summary to each of the following: the primary care provider, all subspecialists who will follow the infant, community health nursing agencies and early intervention services.

CONCLUSIONS

A review of the literature suggests that families are often not adequately prepared for the hospital discharge of their high-risk infant,[32] contributing to poorer infant outcomes, heightened family anxiety as well as increased health-care utilization after discharge. Although the AAP guidelines[26] should serve as the basis for NICU discharge programs, there are substantial

opportunities to improve the NICU discharge process as outlined in this paper. Given that the quality of discharge teaching is the strongest predictor of discharge readiness,[3] it is important to develop a comprehensive discharge preparation program that allows for a systematic and individualized approach for families to help ensure the health of the high-risk infant after NICU discharge.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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